410 Patient and community education about cystic fibrosis (CF) in the North Al Bathina region of Oman: translation of a parent/patient manual

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Effective patient and parent education is an essential component of up-to-date treatment of CF. This holistic approach often is not accessible by socioeconomic less-favored patients. Other factors which negatively impact patient education include illiteracy, communication barriers between patients and non-native physicians, and lack of printed information in the native language. Our recent data for the North Al Bathina region of Oman reveals a prevalence of CF of 1:2460. This finding highlights the need to provide adequate health care education material for Omani parents and their affected children. The present paper evaluates the translation of the CF brochure "A Manual for CF Patients and their Parents" of the CF European network from English into Arabic and discusses difficulties in the translation process. Furthermore, we analyzed the general perception of this translation among 62 randomly selected parents (mean age 32.4 years) waiting in the pediatric outpatient department of Sohar Regional Hospital. The survey revealed that 97% of parents prefer to read medical information material in Arabic. Furthermore, 91% of parents regarded the translated information as very helpful or helpful for the understanding of CF. Only 9% were indifferent in their opinion. Interestingly, 24% of the parents had a previous knowledge about CF. Many of these parents (33%) indicated a non-media source for the information. We anticipate that the availability of the translated parent/patient manual into Arabic will help to spread local awareness about CF and, hopefully, will reach a regional audience through online publishing.

411 Educational support for CF patients

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Roughly 300 children suffering from cystic fibrosis are born in Germany every year. The disease is definitely lethal and on average patients reach an age of 33 years. Because of the high mortality rate and the risk of severe complications, patients need to be educated intensively.

We developed a series of three generally understandable posters to inform patients about cystic fibrosis. Causes and consequences as well as recommendations for diet and therapy are presented in a particular design, which incites patients to read.

The poster "Early stage and diagnosis of CF patients" shows that CF is a recessively inherited disorder which takes effect on different cellular processes, e.g. the chloride channel, the functionality of the exocrine glands and the transport of mucus on the bronchial cilia.

In the poster "Chronic stage and maintenance therapy of Cystic Fibrosis" the infection of the lung is described in detail. Due to the impaired self-cleaning function of the lungs, obstruction of the airways and congestion of the nasal sinuses with mucus, disease-causing agents can cause infections.

The poster "Advanced stage and possible complications in Cystic Fibrosis" shows the substantial changes of the lung, such as bronchiectasis, atelektasis, haemoptysis, fibrosis of the lung and allergic bronchopulmonary aspergillosis (ABPA). Further on complications of the gastrointestinal tract as well as osteoporosis and fertility problems are addressed.

Presenting these posters in the outpatient clinic and distributing them as hand-outs to patients could help to understand the disease and thus improve patients' quality of life.

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412* Pathways Home Project: a pilot study of chronic disease self management in cystic fibrosis (CF)

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Background: Improved survival in CF has resulted in a growing adult population and a need for new models of CF care as a chronic disease of adulthood. Australia's geographically dispersed CF patients present unique challenges to healthcare delivery, particularly reduced access to specialised centres.

Aims: To evaluate the impact of mentorship plus IT-based self-monitoring on CF patients' self-efficacy and self-management behaviours, with the aim of improving clinical outcomes and quality of life in adults and adolescents with CF.

Methods: This multi-sited, community-based, randomised controlled trial is evaluating 2 strategies: mentorship by phone and self-monitoring via an innovative IT tool. Volunteers from nursing and allied health have trained as mentors, focusing on self-management. The IT tool – *Smartphone* – hosts a mobile phone program designed to assist patients with symptom monitoring. Patients send daily text messages to a database, and can view cumulative data, allowing them to note trends and intervene early in disease deterioration.

Participants were recruited via CF clinics, and randomised to 1 group: mentor-only, mentor plus IT tool, or controls. The 6 month intervention has been followed by a 6 month 'washout period', at which point patients are re-assessed for continuing behavioural changes.

Results: Preliminary data indicate that self-management is developing in both active groups.

Conclusions: Initial conclusions from this pilot study indicate the need for future trials in a larger study population.

This approach is particularly suited to adolescents and young adults, who are often techno-savvy but may have difficulty engaging with health professionals.

413 A DVD presentation – an adult cystic fibrosis couples support group: reducing isolation

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Cystic Fibrosis illness has growing ranks of 'survivors' who live longer, fuller lives. Yet, the realities of a life-threatening illness can be that of social isolation; separation from others who share the same disease. Historically, adults with CF have not had occasion to share person-to-person experiences within the structure of their CF care centers. Having that opportunity in an on-going support group does significantly reduce that isolation.

This DVD provides healthcare staff, patients and families a rare glimpse of couples with Cystic Fibrosis (CF) interacting at an American CF Care Center-sponsored support group. Group members discuss

- How CF affects their lives as individuals, as couples, and how the 'non-CF partner' learns from others, and
- Reflections on 'family life and CF'.

This group was formed at the UW-Madison Care Center in 2004. Infection Controls were developed and group members assessed (sputum or throat cultures) at periodic intervals: no cross contamination has occurred as the group enters its fourth year.

Successes: The group is limited to 20 participants; two care center staff facilitate the group. Topics are purposefully not pre-determined; each group's success is based on the personal responsibility of each participant to bring topics/issues from their daily life experiences. The group has gained a firm identity and evolved into two separate groups: an individual and a couples CF group.

Conclusion: Support groups to reduce isolation are feasible, with good infectious disease controls. Goals (2008) include applying formal research methods to study the 'impact' the group has on the overall health (emotional and physical) of the participants.